GOVERNMENT OF INDIA
HEALTH AND FAMILY WELFARE
LOK SABHA

UNSTARRED QUESTION NO:4322
ANSWERED ON:24.08.2005
SPREAD OF HEMOPHILIA
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Will the Minister of HEALTH AND FAMILY WELFARE be pleased to state:

(a) whether the Government is aware that hemophilia is spreading in the country ;

(b) if so, the details thereof;

(c) the total number of persons suffering from this disease till date;

(d) whether the Government has undertaken an in-depth study of this disease;

(e) if so, the details of the findings thereof ;

(f) the measures taken by the Government for combating this disease;

(g) whether the Government is aware that the medicine for its cure called anti-Hemophilia factor(AHF) is very expensive and not available in India ;and

(h) if so, the steps taken/proposed to be taken by the Government in this regard?

Answer

THE MINISTER OF HEALTH & FAMILY WELFARE (DR.ANBUMANI RAMADOSS)

(a)to(c): According to Indian Council of Medical Research (ICMR) there are estimated to be approximately 60,000 patients with severe Haemophilia in the country. However, only a total of 8000 cases are registered with Haemophilia Federation of India.

(d)&(e): A task force study was conducted by ICMR to assess the magnitude of the problem of haemophilia both by the retrospective and prospective studies in the hospital setting, to obtain uniformity and standardization for the laboratory techniques used for diagnosis of the disease and to make efforts to augment the production of blood components in particular cryoprecipitate and to ensure its quality control. The study was done at three centres - Delhi, Vellore and Mumbai. The factor VIII deficiency was observed in 41% cases in Delhi, 27,1% in Mumbai and 31.9% cases in Vellore out of a total number of 295 cases. The recommendation of the study was that there is need for sufficient and special facilities for diagnosis, management, education, research and quality control for laboratory methods, and blood banking and quality control of therapeutic material within the healthcare system of the country.

(f): ICMR have informed that no curative treatments are available for Haemophilia A and B except for liver transplantation. Currently, the standard of care is intravenous replacement of the deficient factor. Factor replacement therapy has increased life expectancy from an average of 1.4 years in the early 1900s to approximately 65 years at present. The strategies for care of Haemophilia include education of patient and his family, health care workers and community; laboratory diagnosis; treatment by physiotherapy and coagulation factors and offering genetic services for carrier detection and antenatal diagnosis.

(g)&(h): The Drugs Controller General (India) (DCGI)has issued import licences to six importers in the country for the import of Anti Haemophilic Factors (AHF) from various countries.